### Stigma Cards

PROJECT CLEAR

"I used to have sex with anyone. It's my fault that I am HIV positive. I'm so stupid."

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PROJECT CLEAR

"Having HIV brands me for life. The best thing for me to do is to crawl into a hole and disappear."

### The Denver Principles

There is no better way to cite the history of the movement for the self-empowerment of people living with HIV than to quote the principles articulated in Denver in 1983. They are as relevant and powerful today as they were then.

We condemn attempts to label us as "victims," a term which implies defeat, and we are only occasionally "patients," a term which implies passivity, helplessness, and dependence upon the care of others. We are "People With AIDS."

### Recommendations for all People:

- Support us in our struggle against those who would fire us from our jobs, evict us from our homes, refuse to touch us or separate us from out loved ones, our community or our peers, since available evidence does not support the view that AIDS can be spread by casual, social contact.
- Not scapegoat people with AIDS, blame us for the epidemic or generalize about our lifestyles.

### Recommendations for People Living with AIDS:

- 1. Form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.
- Be involved at every level of decision-making and specifically serve on the boards of directors of provider organizations.
- 3. Be included in all AIDS forums with equal credibility as other participants, to share their own experiences and knowledge.
- 4. Substitute low-risk sexual behaviors for those which could endanger themselves to their partners; we feel people with AIDS have an ethical responsibility to inform their potential sexual partners of their health status.

### Rights of People Living with AIDS:

- 1. To as full and satisfying sexual and emotional lives as anyone else.
- 2. To quality medical treatment and quality social service provision without discrimination of any form including sexual orientation, gender, diagnosis, economic status or race.
- To full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives.



### Rights of People Living with AIDS - continued

- 4. To privacy, to confidentiality of medical records, to human respect and to choose who their significant others are.
- 5. To die—and to LIVE—in dignity.

# My Rights as a Person Living with HIV or AIDS: Frequently Asked Questions (FAQs)

(To be completed in advance with local information)

### **Employment**

Q: Can I be denied a job or fired for being HIV positive?

A:	No. Your rights related to employment are protected under the Americans with Disabilities
	Act or ADA, which is a federal law. A person with HIV/AIDS, or even suspected of HIV, is
	considered under the ADA to have a disability. ADA applies to businesses that have 15 or more
	employees. Under the ADA, you have the same rights and access to opportunities available
	to others. You cannot be discriminated against during recruitment or when applying for a job,
	hiring, promotions, training, pay, job assignment, and social activities.

There may be additional state laws that protect the rights of people living with HIV/AIDS. Call \_\_\_\_\_ at #\_\_\_\_ to get that information.

Q: Do I have to disclose my status when applying for a job? How about after I am hired?

A: No. ADA protects you from having to disclose your status at any time, whether you are applying for a job or after you've been hired.

Q: Can I be asked about my status during a job interview or on an application? How about to take an HIV test?

A: No. A future or current employer cannot ask you your status or any questions aimed at figuring out if you have any disabilities, which includes HIV/AIDS. For example:

- Do you have any health problems which would make it difficult for you to do this job?
- What medications do you take?

They also cannot ask you to take an HIV test. HIV is not transmitted in a general workplace setting. Asking someone to take an HIV test or to disclose their status is unnecessary and illegal.

Q: Lately I've been experiencing medical problems due to my HIV infection. Can I ask my employer to make special accommodations so I can still work?

A: Yes. Under the ADA, people living with HIV have the right to ask their employer to modify or adjust job requirements or workplace policies in order to allow for them to perform their duties. This is called "reasonable accommodation." An example of a reasonable accommodation request is asking your employer for an adjustment to your work schedule to accommodate doctor appointments.



### Employment - continued

There isn't a fixed list of "reasonable accommodations" and each request is reviewed on a case by case basis. It is the responsibility of the employee/worker to request the accommodation. However, just because a request has been made, it doesn't mean that it will be fulfilled. An employer may turn down the request if it will cause "undue burden," such as, it is financially too expensive to fulfill the request, or it somehow disrupts the business.

Typically, a request involves a signed letter from a physician saying that you are being treated for a disabling condition that requires a specific type of reasonable accommodation that is then described. The exact diagnosis of your disabling condition, e.g., HIV disease, does not need to be mentioned in the physician's letter. Some physicians need to be reminded of this fact.

Before you make a decision to make a request, talk to someone who has experience with this. You can ask your case manager about how to access free or low cost legal services locally.

You can also get advice from the ADA by calling any of these three numbers. Ask to be linked to a regional center that provides HIV/AIDS-related ADA information.

1-800-949-4232 1-800-514-0301 1-800-514-0383 (TTY/TDD)

### Housing

Q: Can I be denied housing because of my HIV status? Can I be evicted because of my status?

A: No. The Fair Housing Act is a federal law that prohibits housing discrimination on the basis of race, color, religion, sex, disability, familial status, and national origin. It covers private housing, housing that receives federal financial assistance, and state, and local government housing. It is illegal to discriminate against selling or renting housing to a person who is living with HIV or AIDS.

Additionally, your landlord cannot harass, evict, or refuse to renew your lease because you are HIV positive.

- Q: I've developed a medical condition due to my HIV infection. Can I make modifications to my apartment to help me out?
- A: Yes. However, the modifications must be "reasonable" and you should speak with your landlord and come up with an agreement before you do anything.

Under the Fair Housing Act, your landlord may not:

- Refuse to let you make reasonable modifications to your dwelling or common use areas, at your expense, if necessary for the disabled person to use the housing. (Where reasonable, the landlord may permit changes only if you agree to restore the property to its original condition when you move.)
- Refuse to make reasonable accommodations in rules, policies, practices or services if necessary for the disabled person to use the housing.



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Q: V	Where can I get more information on my housing rights?
<b>A:</b> Y	You can call the Department of Housing and Urban Development office nearest you.
Τ	The nearest office is located in and their phone number is
Y	Your case manager may also have additional resources for you.
Sex	
Q: D	Do I need to disclose my HIV status with my sex partners?
A: L	Laws about sex and disclosure are decided on at the State level.
F	For the State of, the law states that:
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### CLEAR Thinking Scenarios

**Directions:** Print each situation on a 4x6 card and laminate the cards to protect them from damage caused by repeated use.



You are going to meet a new romantic interest with whom you've shared a few enjoyable dates. You sense that this may be the last date, however, because the pressure of dating someone living with HIV seems too great for your new friend.

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PROJECT

Your health care provider has just told you that your viral load is skyrocketing and you are failing therapy. Your provider thinks you are skipping your meds because you have a reputation for being a heavy partier, and you're "just like most treatment failures." **Directions:** Print each situation on a 4x6 card and laminate the cards to protect them from damage caused by repeated use.

CLEAR

You are loosing your cool with the clerk in the pharmacy. It's Saturday, you have only one day's supply of medications left, and the pharmacy forgot to call in your prescription renewal. The clerk says you're like other HIV patients, "demanding, pushy, and unprepared."

3

PROJECT | CLEAR

You are in a class on AIDS. The teacher asks who's impacted by HIV. A classmate says "queers who are irresponsible and minorities who would rather get HIV than work."

**Directions:** Print each situation on a 4x6 card and laminate the cards to protect them from damage caused by repeated use.

### PROJECT CLEAR

You've started spending some time volunteering and have met a lot of great people. As you get to know them better, you are worried about if and how to tell them you have HIV and what their reaction will be.

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### CLEAR

A new youth minister has convened a fun group of like-minded young adults. After several meetings, you're alone with the minister and disclose your HIV status. After your disclosure, there is a very long pause.

### Scripted Role-Play: Patient and Receptionist

Receptionist: Come over here!

Patient:

(SAY AS IF TALKING TO YOUR SELF) "Don't let this receptionist annoy me. My Feeling Thermometer is at a 40 and starting to creep to a 45. I need to stay cool. Take a deep breath. Smile. Get out of here as fast as possible."

What is it?

Receptionist: How is your health these days?

Patient:

(SAY AS IF TALKING TO YOUR SELF) "Stay focused on giving him (her) quick and easy answers. I'm here to see the doctor not him (her). Take a deep breath. Don't let him get to me."

Fine.

**Receptionist:** Are you really fine?

Patient:

(SAY AS IF TALKING TO YOUR SELF) "Easy does it. I can handle this. It's not worth my time to get in an argument. Don't talk back to him, it will only provoke him (her)."

Yes. I am doing fine.

Receptionist: Really? Your health is holding up?

Patient:

(SAY AS IF TALKING TO YOUR SELF) "Ignore the way he (she) says that. Stay focused on my goal. Take another deep breath. I don't like this guy so I need to exit the situation. Stay cool."

Yes, my health is OK. I'm here to see the doctor. I will be in the waiting area. I would appreciate if you could let me know when my turn is up.

**Receptionist:** Yeah I will call your name. Take care of your health and don't pass anything around.

Patient:

(SAY AS IF TALKING TO YOUR SELF) "I did pretty well. I stayed cool and stuck to my plan. I was able to keep my Feeling Thermometer at a 45, and now it's back down to 40. I am happy with the way the situation turned out. Great, now I need to accomplish what I came here to do!"

Thank you. I will.



## Advantages and Disadvantages of Disclosure

Advantages	Disadvantages

### Disclosure Comfort/Importance Grid

Disclosur	e Comfort/Import	ance Grid
Disclosure Targets	Feeling Thermometer	Importance Yes/No
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## Disclosure Target: Advantages and Disadvantages

Disclosure Target: Advantages and Disadvantages  Target:					
Advantages	Disadvantages				

## Guidelines for Disclosing That You are HIV Positive

#### Who to Tell

Some people you might want to tell include:

- Sexual partners. If they're at risk, they should know you're HIV positive. They should know so they can get tested.
- Health care providers. Doctors, nurses, nurse practitioners, and alternative healers all need to know. They might be at risk for infection. You want the best care you can get. If they don't know you have HIV, you might not get the best care.
- Anyone who can help you plan your future. Tell anyone who will help you decide what happens to your possessions, children, apartment or house.
- Anyone who can help you right now. Tell anyone who can help you out if you're sick.
- Anyone who's important in your life.

These are all important people to tell. But you do not have to tell anyone if you don't want to. You only have two obligations: You need to take care of your health, and you should not put others at risk.

#### Before You Tell

Here are some things to think about before telling someone you have HIV:

- Will they keep the news to themselves? Don't tell if you think they'll tell others without your permission.
- Are they in a position to make your life difficult? They might react badly. For instance, your landlord could make apartment life uncomfortable. HIV discrimination is illegal, and it happens.
- Will you get beat up or worse? Don't put yourself in any danger.

#### When to Tell Someone You Have HIV

Knowing when to tell can be hard. Here are some things to think about:

- Why do you want the person to know?
- Are you prepared for all the possible responses they could have?



#### When to Tell Someone You Have HIV - continued

- Are you prepared to have the person reject you?
- Are you prepared to have the person feel much closer to you?
- Are you prepared for all the emotions this talk might bring up?

Be prepared to give the person a lot of support. This might seem strange since you're the one with HIV. You've known for a while, though. They're just finding out.

#### How to Tell Someone You Have HIV

When you tell someone you have HIV, they'll usually take their cues from you. If you're calm about dealing with HIV, they will be calm. If you're not ashamed of having HIV, they won't think it's anything to be ashamed of. It's important to "be in the right space" beforehand. You have a lot of control over the outcome.

- Make sure the time is right. Don't rush into it and don't rush through it.
- Make sure the place is right. Find a private spot.
- Let the person know beforehand. Tell them you have something very important to discuss.
- Make sure the time is right for you. If you don't feel well, try to reschedule.
- Practice in advance. Rehearse with a friend what you will say.
- Be honest and direct. Beating around the bush doesn't make it easier.
- Ask how the other person is feeling. Knowing what emotions you are dealing with can help you cope.
- End with a discussion of the next step. This helps move the conversation along and give you a graceful exit if necessary.

You are not responsible for how they respond. No matter how they react, they'll probably need time to think.

Sometimes it's appropriate to disclose your HIV status in a letter. Try to follow up with a phone call or a visit to find out how the person is reacting. If you write and don't follow up, they may feel cut off. Give them a chance to respond.



### Relaxation Sequence: On the Beach

Get yourself in a comfortable position. Pause. Observe your breathing. Pause. Now, breathe out deeply three times. One. Pause. Two, Pause. Three, Pause. Close your eyes, if you wish, as we take a little journey. You are in a little house by the beach. Pause. You open the door to the deck, and, before you can even step outside, the sun greets you warmly. See how blue the sky is. Pause. Just a few wispy clouds. Smell the tangy salt air. Pause. You walk to the edge of the deck and step down into the fine white sand. Feel the warm sand between your toes. Pause. You hear the surf breaking and the sea gulls crying. See the waves slowly rolling on the shore. Pause. You walk on the soft sand, moving closer to the ocean, and spread your towel. You sit watching the soothing rhythm of the sea. Breathe in and out. Pause.



In and out, Pause.

In and out. Pause.

You lie there on the empty beach.

Your whole body becomes one with the sun, waves, sand, and sky.

Can you see the gulls gliding without effort, nodding on the breeze as if they were asleep? Pause.

Can you see the gulls gracefully swoop and bank and turn? Pause.

Feel the breeze blowing softly, cooling, and cleansing you.

You seem to sink into the sand.

Can you feel your breath becoming deep and slow? Pause.

Can you feel your heartbeat--regular, an easy rhythm, strong? Pause.

You rest. Pause.

You rest a little longer. Pause.

Slowly you sit up. Pause.

You see a little purple shell carved by the sea, so that it seems to have magical writing on it.

Put it in your pocket.

You stand up. Pause.

Walk slowly back to the beach house. Pause.

The sand covers your feet and you dig with your toes.

You are almost at the step to the deck.

Step up. Pause.

You look back at the ocean feeling so refreshed.

So peaceful. Open the door to the house and go in.



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### Using CLEAR Thinking to Help with Staying Healthy

Practice replacing these unhelpful thoughts with CLEAR Thoughts:
Unhelpful Thought: "It's too hard to take a walk every day."
Unhelpful Thought: "I can't keep to a daily exercise routine."
Unhelpful Thought: "I've been such a failure at exercising in the past."
<u>Unhelpful Thought</u> : "Staying healthy is to hard."
Practice replacing your unhelpful thoughts about staying healthy with CLEAR Thoughts:
1. Unhelpful Thought:
CLEAR Thought:
2. Unhelpful Thought:
CLEAR Thought:



3. Unhelpful Thought:		
	*	
CLEAR Thought:		
4. Unhelpful Thought:		
CLEAR Thought:		
5. Unhelpful Thought:		
CLEAR Thought:		

### Using CLEAR Thinking to Help Break Down Barriers to Medical Appointments

Practice replacing these unhelpful thoughts with CLEAR Thoughts:			
Unhelpful Thought: "I can't stand my doctor. He's so judgemental."			
Unhelpful Thought: "I can't stand it when he lectures me."			
<u>Unhelpful Thought</u> : "I've been such a failure at working with my providers in the past."			
Unhelpful Thought: "Managing my medical care is too hard."			
Practice replacing your unhelpful thoughts about barriers to medical appointments with CLEAR Thoughts:			
1. Unhelpful Thought:			
CLEAR Thought:			
2. Unhelpful Thought:			
CLEAR Thought:			



3. Unhelpful Thought:	
CLEAR Thought:	
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4. Unhelpful Thought:	
CLEAR Thought:	
5. Unhelpful Thought:	
CLEAR Thought:	

### Guidelines for Being a Partner in Your Medical Care

Suggestions:					
- Continue	7001		 - History		
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### More suggestions:

### Believe in yourself.

Your medical care is all about you. You are worth it. Believe in yourself and your capacity to get what you need.

#### Make a plan to succeed.

- Make it a goal of yours to get the best possible treatment and care.
- Make a goal before each appointment so you know exactly what you want to accomplish.

#### Follow your plan.

- Inform your provider. Tell your health care provider about any recreational drugs you are using or alcohol you are consuming. There are certain HIV meds that interact with recreational drugs and your provider may have to alter your meds.
- Tell your health care provider what you think might help him or her give the best care, e.g., symptoms (be specific), allergies, previous illness.

#### Question your provider.

- Make a list of questions you want to ask before your appointment.
- If you don't understand something, ask your provider to explain the information so you can understand it.
- Keep asking until you understand.

#### Be assertive.

Make it clear you want to be included when important decisions are being made about your care.



### Be cautious.

Don't sign consent forms unless you know what they mean.

#### Follow-up.

Health care providers often say they will do things and then don't carry them out. It may be that they are too busy or the system doesn't work right to help them. It is critical to follow-up and continue requesting that they do what they agreed to.



### Rights and Responsibilities of People Living With HIV

#### You have certain rights as a patient:

<u>You have the right to the best medical care treatment possible</u>. You have the right not to be discriminated against based on your sex, sexual orientation, religion, ethnic or national origin, source of payment, or history of drug use or of incarceration.

You have the right to know about your medications, what they do and their side effects. Ask your health care provider or pharmacist about side effects.

- You have a right to answers in words you understand.
- You have the right to refuse treatment or tests at any time.
- You have the right to disagree with your health care provider or to get a second opinion.
- You have the right to be treated with respect.
- You have the right to take anyone with you when you talk with your health care provider.
- You have the right to complete confidentiality.
- You have the right to choose the best medical care for you.

### You also have certain responsibilities as a patient:

- You have the responsibility to be completely honest with your health care provider. Tell your provider about all medications, alternative treatments, and vitamins you're taking. Tell your provider about any allergies you have, and any alcohol or recreational or party drugs you use.
- You have the responsibility to listen to what your health care provider says.
- You have the responsibility to treat your health care provider with respect.
- You have the responsibility to tell your health care provider when you aren't doing or taking something that was prescribed. You should tell your provider why.
- You have the responsibility to choose a health care provider who works with you on your terms.
- You have the responsibility to ask questions until you understand.



### Characteristics of Communication

Characteristics of Communication					
Aggressive	Assertive	Passive			
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## Role Playing: Assertive Communication

### The Busy Doctor

#### Patient:

My goal is to have the doctor explain to me how I am supposed to take my medicines.

- I am the patient and have been sitting in the waiting room for an hour. It's finally my turn to meet with the doctor.
- It seems like she's in a rush and doesn't have time to answer any of my questions.
- She also prescribed me a new medicine and I don't understand how I am supposed to take it.

#### Doctor:

My goal is to give the patient the best care possible, but quickly.

- You are the doctor. It has been a very busy day.
- There was an emergency at the hospital that you had to deal with and now your schedule is backed up. You need to see 4 more patients this hour, or else your supervisor is going to give you a hard time.
- You just prescribed a new medicine to the patient you are with and the directions are on the bottle. Also, you figure the pharmacist can answer any other questions the patient might have about how to take the meds.



## How Do I Maintain My New Behavior?

The behavior I want to maintain:		
	What are the positive outcomes of the behavior I have	ve changed?
	What things will reinforce my changed behavior?	
	Who reinforces my changed behavior?	
	In what situations are my changed behaviors reinforce	ced?

